

Leetha Wren Joins ASCC

Leetha Wren joined the staff of the Arkansas Spinal Cord Commission (ASCC) in November. She has assumed the Case Management duties in the Batesville Office, covering a ten county area in North Central Arkansas.

Leetha holds a Masters degree in Social Work from UALR Graduate School of Social Work and is a Licensed Social Worker with 22 years experience with the State of Arkansas. Previously she has been employed with the Services for the Blind and Children's Medical Services. Leetha's background and vast experience will definitely

benefit the 170 individuals with spinal cord disabilities on her caseload.

In her spare time Leetha enjoys reading, watching movies and going to the Ozark Mountain Folk Center. She also enjoys spending time with her family, going to yard sales and playing with her cat, Rehab.

The Commission feels very fortunate in having found someone with such a strong case management background. Please join the Spinal Cord Commission members and staff in welcoming Leetha!



ASCC Case Manager Leetha Wren will be working out of the Batesville office.

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Fitness After SCI: How to Get Started

By Catherine Warms, PhD, RN, ARNP, CRRN, UW School of Nursing, and Cynthia Salzman, MHA, UW Rehabilitation Medicine

We all know physical activity is important for good health. This is as true for people with SCI [spinal cord injury] as it is for the general population. But the barriers to getting exercise and staying fit are especially challenging for those with SCI.

Because moving about is difficult for people with SCI, they can easily fall into a "cycle of deconditioning" [see Figure 1 on page 4], whereby inactivity causes changes in the body that make it even harder to move about and be active, and this further dampens the motivation to be active.¹ The process of losing fitness may begin with the sudden changes in muscular function caused by SCI, but it is perpetuated and aggravated by lack of

physical activity. Furthermore, long-term inactivity produces harmful effects on body function and structures: slowing bowel motility; weakening bones, joints, and muscles; and causing the heart and lungs to work harder.

Effects of Physical Activity

Research has shown that regular physical activity decreases the risk of heart disease, diabetes, high blood pressure and colon cancer; reduces depression and anxiety; helps control weight; and helps build and maintain healthy bones, muscles and joints.

In the SCI population, physical activity results in improved breathing ability; greater muscle strength

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SPINAL COURIER

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If you would like to make a contribution, please contact the Commission at **501-296-1788 / 1-800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

**AR Spinal Cord Commission
1501 N. University, Suite 470
Little Rock, AR 72207**

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Become a Member of SBAA

Dear Editor:

The Spina Bifida Association of Arkansas (SBAA) plays an important role in the lives of Arkansans with spina bifida. It promotes family activities, such as Family Fest and the Christmas Party, and provides education scholarships and family support, plus other services.

You, too, can be a part of SBAA: become a member for only \$20! This annual membership fee is due by **March 15, 2005**. Contact me at **501-978-7222** for more information.

*James Rucker, President
Spina Bifida Association of AR*

From the Director

We watched him soar in movies as Superman and were amazed when we found he was a mere mortal and had broken his neck. Christopher Reeve joined the exclusive club of spinal cord injury in May of 1995 and many of us in the SCI community wondered what he would do or how he would do it.

In the nearly ten years that he lived with his disability, he proved that he truly was Superman. No one has had more impact on both the 'care' and the 'cure' communities. No one has more effectively brought life with spinal cord injury to the forefront and into the media than Chris Reeve. People didn't 'feel sorry' for Chris Reeve—they were in awe of him. He leveraged his celebrity status to raise awareness and support for thousands of people with spinal cord injuries.

While even he admitted that 'a cure' might not come during his lifetime, he was willing to serve as a 'human guinea pig' if it did. And he worked long and hard, raising private money, advocating for public money and stem cell research and putting together the scientific teams who could use what was learned over the past 20 years to finally move the research to human subjects.

Along the way he established the Christopher Reeve Paralysis Foundation and the Christopher and Dana Reeve Paralysis Resource Center and gave away hundreds of thousands of dollars in Quality of Life grants (Dana Reeve called them 'freedom' grants) to organizations helping people with disabilities improve their lives. And he continued to make movies, right up until his death.

I could go on and on, but the fact is, Christopher Reeve 'got it.' He quickly came to understand the issues and he acted accordingly, having an impact that will be his legacy, far more important than any of Superman's deeds. He will be missed.

Cheryl L. Vines

Way to Go, Amanda!

Amanda Moore does not define herself as “disabled.” She is a daughter, a student, a girlfriend, an animal lover, and—above all—a survivor! She was 20 years old when she was injured in February of 2003. An ATV was pulling her on a sled in the snow, when she was thrown from the sled, which resulted in head injury and a C-5/6 fracture to her spine.

After three months of rehab at Baptist Rehabilitation Institute, Amanda returned home to Searcy, AR to begin the process of restructuring her life. Struggling with bouts of depression and anxiety, Amanda sought consolation from Erin Gildner, another young female client of the Spinal Cord Commission. Erin, who was injured in a motor vehicle accident in April 2002, was able to mentor Amanda through sharing her personal struggles and accomplishments that she experienced during the first year after her injury.

Amanda believes it was her interaction with Erin that helped her realize, “I was not the only person learning how to live life with a disability. . . . More importantly, I could continue to lead a productive and healthy lifestyle with a disability. Erin was living proof of that fact.”

Amanda also credits her family in the equation of her success to date. While Amanda was recovering in the hospital, her family transported her personal belongings from a second floor apartment to an accessible first floor apartment. They never lost faith that Amanda would regain her independent spirit and want to become as self-sufficient as possible, and continue to encourage her through times of self-doubt.



Amanda Moore of Searcy shares her experiences and insights on the Web.

Amanda was enrolled as a student at the University of Arkansas in Fayetteville at the time of her accident. She is now back in pursuit of her high-

er education, taking core courses at Arkansas State University in Beebe. Her accident left her with limited dexterity in her hands, which put her former plan of becoming a veterinarian into question. Her strongest field of study is math, so she now is considering other career options such as architecture, computers and accounting.

Amanda acknowledges that she could not have come this far on her own. One of her main goals is to help the disabled community by sharing her experiences and insight with those who are seeking guidance as she was. Like many of ASCC’s clients, who are either working or going to school during the day, Amanda is not able to attend the SCI support groups offered each month. So, she’s found her own form of support group online through CareCure Community (<http://sciwire.org>).

The CareCure website holds a wealth of information and includes forums that provide up-to-date information on SCI and related disorders. Amanda is a prominent member on this site, for as she relates, “I [initiated] the development of chapter forums in regard to demographic location. I asked Wise Young (he is a well respected SCI researcher at Rutgers University, as well as founder and main moderator of CareCure) if there was any way to look up members by the state they have listed as their

Shannon Checked It Out for Herself

My name is Shannon Cleveland and I have C-4/5 quadriplegia. For the past year I have been learning about my injury and all that applies. CareCure Community is a place on the Internet that I found that has helped me in more ways than one. It is a forum where you can post questions about care, caregiving, life, exercise and equipment, and it is all for those with SCI.

You will get immediate responses from the SCI Nurses, members from all around, and sometimes Dr. Wise Young who is the administrator and founder of the community. All of the nurses and Dr. Young are well versed in the studies and care of SCI.

It is a great resource and wonderful support. It allows you to make friends with the same concerns most persons with SCI’s have, as well as getting answers to questions you might have. I have gained so much knowledge from this community that I had to teach my doctor about a few things. I hope that this will help everyone searching for answers on the subject of care or life in general. The website address is: <http://carecure.org>

home. . . . Thus, he created various chapters according to people’s requests.” The CareCure Chapters forums are where people can meet and share information with others in their region.

Amanda has constructive and creative ideas to help enhance the SCI community, and welcomes your correspondence (amandamoore26@sbcglobal.net) and feedback. Way to go, Amanda!

Fitness After SCI

Continued from page 1

and stamina; improved blood circulation; decreased body fat; more normal levels of fats (lipids) in the blood; improved self-esteem; decreased depression; improved immune system function; decreased risk of diabetes; slowing of bone loss, and better bowel function.

Physical activity also has been shown to help prevent common secondary conditions related to SCI, such as urinary tract infections, pressure sores, respiratory infections and constipation. These problems are more common in people who are inactive, and people with SCI who are most active (athletes) have fewer of these problems than those who are less active.²

There are some physiological responses to exercise that are unique

How to rate your exercise intensity:

People with SCI usually cannot use heart rate as a measure of exercise intensity. In the absence of a standardized scale for the SCI population, a good way to gauge workout intensity is to pay attention to what your body tells you about how hard you are working; this is called “perceived exertion.”

Rating exertion on a 0 to 10 scale—where 0 = no intensity, 2 = light intensity, 3 = moderate intensity, 5 = heavy or hard intensity, and 10 = very, very high intensity—has been shown to be a valid and reliable indicator of exercise intensity.⁴

Inactive people should begin with light intensity activity and gradually increase to moderate intensity. More fit folks can safely work in the 4 to 6 (high intensity) range.

to SCI. People with an injury at T-4 or above are less able to increase heart rate and control blood pressure while exercising, and blood in the legs does not return to the heart and lungs as easily. As a result, the positive cardiac effects are not as strong as they are in people who have more autonomic nervous system control.

SCI may cause changes in the sympathetic nervous system that can keep blood pressure low during very hard exercise. This low blood pressure may not be noticed and returns to normal after exercise ends. Such exercise responses need not prevent low to moderate level activity, but those wanting to do more strenuous continuous exercise (such as marathon wheeling or handcycling) should consult with a physical therapist or physician knowledgeable about SCI to get specific advice about how to minimize lightheadedness or other problems related to low blood pressure or heart rate.

Lifestyle Physical Activity—A Practical Approach to Exercise

Deciding to become more active raises many questions: What do I need to do to get fit? What will help me become more active? What things might get in the way? The answers may surprise you and help you take the first step toward increasing your activity levels.

In recent years health researchers have shown that fitness (defined as the physiological improvements that result from activity) can be achieved without embarking on a formal exercise program. Called “lifestyle physical activity,” this approach includes any movement of the body that is produced by

The “Cycle of Deconditioning”



the muscles and uses energy.

While “exercise” is often a planned, structured, repetitive activity that may require knowing specific movements or skills, lifestyle physical activity can occur anywhere and be a part of whatever you are doing. One example is doing household chores that involve torso or arm movement, especially with the arms above the level of the heart. Adding “wheeling” time to your day is another way to increase activity.

Physical activity can range in intensity from low to high [see left sidebar: “How to rate your exercise intensity”] Low or moderate intensity activity is the best way to become active because it helps build confidence and reduces the chance of injury. Moderate activity produces the same health benefits as high intensity activity, and it does not have to be done all at once to be beneficial. Studies have shown that three 10-minute sessions of activity worked into the course of a day may have the same health benefits as longer sessions. People who begin physical activity with this approach (moderate intensity, short sessions) are more likely to adopt activity as a habit and may choose to pursue more vigorous activity (like exercise or sports) at a later time, often because they feel better and have more energy. The “lifestyle” approach to increas-

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Fitness After SCI

Continued from page 4

ing physical activity was recently tested in a research study that included 16 people with SCI (C-6 level or below) who were not regular exercisers.³ The nurse researcher helped participants develop a personal plan for becoming more active based on preferences, schedules, opportunities, motivators, and barriers to becoming active.

After six weeks on their personalized programs, 60% of participants significantly increased their level of activity (recorded with an activity monitor). They had significant increases in upper extremity muscle strength and improvements in self-rated health, confidence, and motivation to exercise. Participants reported that the lifestyle physical activity approach was easy to do and did not interfere with other activities.

Study participants chose an interesting assortment of activities that fit their schedules: using exercise tubing while doing something inactive (watching television or taking a break from computer work); lifting weights or doing stretching exercises to break up an inactive period; increasing wheelchair wheeling time by mall wheeling, parking farther from a destination, or doing a lap during downtime at a youth sporting event. Some chose traditional exercise (exercise videos, upper extremity ergometry, mat exercises, bed push-ups, wheelchair arm "dips," using a standing table or a walker), sports (skiing, target shooting, swimming), or lifestyle activities (housework, gardening, arm movements during television, painting), or a combination of these. Those who had been the most inactive increased their activity levels by spending more time out of bed. While this study did not examine weight loss or cardiac fitness, it did demonstrate that the lifestyle activity approach is a feasible way

Getting Started

- ◆ **Ask: What can I do now?** Begin by doing it three to four times a week, then increase duration or intensity by 10% to 20% each week. Gradually add new activities.
- ◆ **Consult a health care provider if you have arm or shoulder pain.** Overuse is often caused by doing things the wrong way rather than too much.
- ◆ **Prevent overuse syndromes:** Vary your activities from day to day, strengthen your upper back and posterior shoulder muscles, and stretch the muscles in front of your shoulders and chest.
- ◆ **If you have tetraplegia (quadriplegia):** Exercise in a cool environment to prevent overheating. Take measures to prevent low blood pressure by wearing support hose, ace wraps and an abdominal binder. Stop exercising if you develop dizziness, nausea, or light-headedness. Know the symptoms of autonomic dysreflexia (AD). Exercise does not commonly induce AD, but this can occur in some individuals.
- ◆ **Follow the START plan:**
 1. **Schedule:** Where does activity or exercise fit into your day? When are you sitting still way too long? Could you add activity to an inactive task?
 2. **Timing:** Is this the right time in your life to make a change?
 3. **Activity:** What do you like to do? Do you prefer outside or indoors? Alone or in a group?
 4. **Resources:** Determine whether you need equipment, classes, videos, a helper, etc.
 5. **Tracking:** Keep track of your activities. Create benchmark goals, and reward yourself when you follow through with your plan.

to increase physical activity and exercise in people who have significant barriers to improving their physical fitness.

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Web Resource:

The National Center on Physical Activity and Disability (www.ncpad.org) is a one-stop information center concerned with physical activity and disability, and offers resources, links, discussion forums, exercise guidelines, and more.

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Up Close and Personal: Sharon McCoy

This is the fifth in a series of articles profiling the ASCC Case Managers.



In 1996 Sharon McCoy joined the Commission as Case Manager in the West Memphis office. While providing case management services to 157 individuals with spinal cord disabilities in Northeast Arkansas during the past eight years, Sharon has developed positive working relationships with her clients.

“Sharon’s enthusiasm and positive attitude are qualities she shares with her clients on a daily basis. She is tireless in her efforts to provide services to her clients,” observed Client Services Administrator Patti Rogers.

Sharon obtained her degree in Psychology from Memphis State University. Prior to assuming her role as ASCC Case Manager, Sharon was employed as a Counselor for the Seven Hawks Wilderness Program for delinquent youths in Tennessee. This experience and her intervention techniques and counseling skills have served her well at ASCC in performing her case management duties.

Sharon reflected that her advice to a new Case Manager would be, “Listen to your clients as they often know best. You may think you know what their needs are, but you really don’t. What works for one person doesn’t always work for another. Every case is individualized.”

PROFILE

Date And Place Of Birth: March 23, 1964, West Memphis, AR.

The Animal I Most Identify With Is: A bird: they are industrious, social and giving to each other as a member of the flock, yet they can be perfectly content to live independently in their own nest

I Absolutely Will Not Eat: Possum or squirrel stew (my roommate in college offered me some once)

If I Did Not Live In West Memphis, I Would Want To Be: In New Zealand

My Favorite Movie Is: *The Autobiography of Miss Jane Pittman*

My Favorite Song Is: *Falling in Love with Jesus*

The Guest At My Fantasy Dinner Party Would Be: Jesus

I Am Most Comfortable With People Who Have: A good, pleasant sense of humor

My Favorite Pastimes Are: Watching old movies, westerns and reading

My Pet Peeve Is: Intolerance

The Best Advice I Ever Received Was: Always have your own money (my Mom told me that)

My Favorite Saying Is: I get some right, I get some wrong

I Knew I Was Grown Up When: I bought my first car, a Ford Festiva

The Latest Book I’ve Read Is: *Walkin’ the Dog* by Walter Mosley (he is a mystery writer)

The One Thing I Always Wanted To Do But Have Never Had The Chance Was: Go to Medical School

My New Hobby Is: Collecting teapots

One Word To Sum Me Up: Generous

Ms. Wheelchair Arkansas Mare Simonar-Dykes

ASCC client Mare Simonar-Dykes was crowned Ms. Wheelchair Arkansas 2004-2005 on June 19, 2004, in Jonesboro. In her new role, Mare said, "I [have been] traveling throughout the state promoting positive awareness

many necessary causes, and the Ms. Wheelchair Arkansas pageant."

Her motto, "Advocacy Through Living," aptly describes Mare's life and her new role. Mare has been documenting all events and appear-

ances in scrap-book form. Also, she will be representing Arkansas at the Ms. Wheelchair America competition in July 2005 in Albany, NY.

Mare and her family live in Beebe where she and husband, Darin Dykes, are amateur radio operators and have been

out the 1999 tornados that struck Beebe and surrounding areas." Mare is the mother of two energetic boys, ages 9 and 2, plus she is the owner of a home-based business called Native Maiden.

The upcoming Ms. Wheelchair Arkansas pageant is scheduled for June 16-18, 2005, in Jonesboro. This is not a beauty contest based on talent or swimsuit competition, but instead on advocacy, skills and abilities. The pageant allows women to see their potential, share their accomplishments and challenge their personal growth.

The application deadline is **April 30, 2005**. For more information and an application, contact Ida B. Esh't, State Coordinator, at **501-296-1637** or **501-296-9913**, or contact Katherine Napper, Publicity Chairman, at **870-972-8811**.



Mare Simonar-Dykes, Ms. Wheelchair Arkansas 2004-2005, and Grace Blackmon of Heber Springs attended the SBAA Family Fest on October 30, 2004, at Camp Aldersgate.

regarding the abilities and accomplishments of persons with disabilities." She added, "As Ms. Wheelchair Arkansas I believe that my paramount concern is addressing any disability issues within the community and how I can better serve the community as a whole, as well as promote awareness to

involved in many community service events, providing communication for such events as the Susan G. Komen Race for the Cure, the MS 150 and many more. She adds, "Most vitally we have provided our time and services to storm spotting and disaster aftermath, having given of ourselves through-

Time to Sign Up for Camp!

It's time to start thinking about Spina Bifida Camp! Camp this year will be **June 26 to July 1, 2005**. Applications will be sent out in February. If you have any questions regarding camp, please call Mary Jo Stanton at **501-296-1788** or **800-459-1517** or by e-mail at mjstanton@arspinalcord.com.

Oops!

There was an error in the October 2004 *Spinal Courier* regarding the Rollin' Razorbacks coach's phone number. Coach Jared Johnson's phone is **501-240-1529**. Sorry for any inconvenience. On **February 12, 2005**, the AR Valley Conference Tournament will be held in Little Rock. Mark your calendar and come watch them play!

Take this Survey: Nobody Left Behind

Be it recollections or current experiences, the University of Kansas' Research and Training Center on Independent Living wants to hear from persons with mobility limitations who have experienced a disaster. The online survey at www.nobodyleftbehind2.org, under "Consumer Survey" is easy and fast to take and will help shape the future of emergency planning!

Survey participants will remain anonymous, but their stories will be told to the public, policy mak-

ers, emergency managers and responders. Are there accessible public or para-transit transportation systems for getting to and from shelters, medical care and so on? What obstacles are there with receiving services at a shelter, or services to re-enter your work or home after a disaster? What did and did not work for you in a disaster situation?

The research team at University of Kansas wants to know this and more. Let your voice be heard—take the survey!



The Squeaky Wheel

The squeaky wheel . . . gets the grease! That's what this new column is about—grease. Things that make life for persons with a spinal cord disability go smoother. Things that ease your way in the world and that you are willing to share. "Things" can be anything—hints, equipment adaptations, innovations, tricks-of-the-trade, procedural shortcuts, life experiences, or things you "should have done but didn't."

Our first offering of "grease" falls in the missed opportunity category. Fred reminds us that we all need to be our own best advocate.

My name is Fred and I have a T-5 midlevel complete paraplegia. Recently, I was an inpatient in a large metropolitan hospital for a colostomy (related to a burn injury in my groin area). During my recovery phase while still on a Foley catheter, I noticed that my nurses were not draining as much urine out of the bag as was usual, but I did not pay it any mind, nor did they. Since my regular doctor was out of town, another doctor, unfamiliar with my history, had

charge of my care. Two or three days later, I began feeling really bad and drifted in and out of consciousness. Some of my family members thought I looked so bad that I might not make it.

Finally, I was admitted to ICU and an ultrasound indicated that I had a very extended bladder and a partially collapsed catheter tube. I was told that nine liters of urine was drained off over the next 24 hours. Thank goodness my bladder

did not rupture! This avoidable episode cost my family and me much grief and an extra week in the hospital, three days of which were in ICU.

I learned to **never** again **hesitate to voice my concern** if I notice a significant change in my urine output, or for that matter, any other unusual symptoms, even if the medical staff does not take note of them.

Thanks to ASCC Case Manager Robert Griffin and his client Fred for sending in this suggestion. **We invite you to send in your helpful hint—your bit of "grease."** Contact your ASCC Case Manager, write us or e-mail us at courier@arspinalcord.org.

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